Why Does Spirituality Matter in End of Life Care?

Joris Gielen

Problems in the Study of Spirituality in Palliative Care

In publications and lectures about palliative care, the WHO definition of palliative care, which mentions spirituality as a central component of holistic palliative care[1], is often quoted almost like a sacred mantra. Nowadays, it will be very unlikely to come across anyone involved in palliative care – physicians, nurses, volunteers, researchers – who will question the importance of spirituality in end of life care. Yet, when we delve deeper into the matter, there seems to be much confusion and doubt among palliative care providers regarding spirituality. What exactly is spirituality and why would it be so important? In the literature, we find tentative answers to these questions, although not rarely authors admit that they do not really have a proper solution and spirituality is often said to defy definition.[2] At first sight, such an admission may seem an elegant way to bypass a complex issue. But, we have to be aware that this does not really help counsellors, physicians and nurses who have to provide spiritual care and researchers who have to study it. These groups of people would be best served with concrete answers to the questions regarding the nature and importance of spirituality in palliative care.

An elaborate study on the definition of spirituality in palliative care falls outside the scope of this presentation. However, if we want to determine why spirituality matters in end of life care, we will have to delineate our field of study so that we can be sure that we are indeed studying spirituality and not something else. On the basis of a critical review of the literature, I propose to define spirituality in the following way. Spirituality is the dimension of human life in which humans consider, experience, feel or deny the existence of a power, force, principle or entity which transcends human life and the world.

This definition of spirituality in many ways includes existential issues and search for meaning. It also includes, but is not limited to aspects of religion. It allows us to make a distinction between spirituality and other aspects of health care, such as the physical, ethical, psychological and social. For instance, when a patient expresses his desire for reconciliation with his estranged brother, this is a social issue. When this patient states that the love he feels for his family is stronger than death, this is an expression of spirituality, because the patient refers to something “which transcends human life and the world”, i.e. a particular kind of love. However, the borders between these various aspects of health care are not always absolute.

When spirituality is interpreted in this way, we can wonder why the palliative care team should pay attention to it. Is spirituality not rather something personal from which the palliative care team should shy away? Some patients may indeed not be interested in discussing spiritual matters with the palliative care team. However, as I will show below, spiritual issues can strongly determine how patients emotionally respond to their disease. Spirituality can contribute to an increase or a decrease of the emotional burden caused by the disease and can seriously impact patients’ quality of life in

that way. In order to understand this, we have to take a look at the manners in which palliative care patients deal with diagnosis and prognosis. Insight in this process will help palliative care providers to give proper support to patients who are experiencing spiritual problems.

Stages of Grief

Patients who have reached the terminal stage of a prolonged illness face severe problems which have a large impact on their physical and mental wellbeing. In her seminal work *On Death and Dying* (1969) Elisabeth Kübler-Ross attempted to describe the various stages patients emotionally go through when they are confronted with a terminal illness. These stages are now very well known by people providing end of life care. According to Kübler-Ross, when patients are confronted with the diagnosis of a life-threatening illness they first go through a stage of denial. At this stage, patients attempt to live as if no diagnosis has been made or they presume the diagnosis must have been wrong. They try to get confirmation that the diagnosis was not correct for instance by going for a second opinion. When the patient is confronted with increasing limitations brought about by the illness the stage of anger ensues. The patient fiends his illness unfair, wonders why this has to happen to him, and vents his anger on care givers or God. Then comes the stage of bargaining. Still being unable to accept the unavoidability of the deterioration of health and impending death, he desperately searches for ways to extend his life span and avoid suffering through promises, such as promises to God for religious fervour or a healthy life style. This bargaining does not work, and in the subsequent stage the patient gets depressed. He no longer feels involved in the world. He continuously ponders on what has been lost, such as physical strength, appetite, comfort, and what will be lost: life and all relationships. In the final stage, the patient reaches acceptance of his condition. This is a stage of peace: the patient gradually and quietly detaches himself from life.[3,4]

All over the world, Kübler-Ross' insights have helped professionals and volunteers involved in end of life care to better understand their patients' feelings and emotions. This can be illustrated by the fact that the work of Kübler-Ross has been translated into 35 languages, including Malayalam and Urdu.[5] Yet, we should not lose sight of the fact that Kübler-Ross reached her conclusions through observations of North-American patients. Her findings may need some qualification in countries such as India with a very different social, cultural and spiritual setup. Thus, there is a need for studies on how terminally ill patients in India deal with diagnosis and prognosis.

In 2012, we undertook a study at the pain and palliative care unit of the Dr B.R. Ambedkar Institute Rotary Cancer Hospital, All India Institute of Medical Sciences (New Delhi) to collect evidence regarding the ways in which Indian advanced cancer patients deal with diagnosis and poor prognosis. We were not so much interested in numerical data, but instead focussed on the patients' narratives, i.e. their life stories. We undertook semi-structured interviews of 31 patients and collected data through participant observation. This meant that relevant information was gathered through observation of and participation in the interaction between patients, their relatives, physicians and nurses. We observed that among patients in Indian palliative care there are mainly four ways of dealing with diagnosis and prognosis: suppression, denial, hope and acceptance. In what follows, I will describe these four responses and explain the ambiguous role of spirituality in this context.

Suppression and Denial

Suppression or avoidance means that the patient actively attempts not to think about the illness and its consequences. This is not always possible, as pain and other symptoms often force patients to face their disease. This experience was expressed by Ambika, who was 32 years old at the time of the study and suffered from chondrosarcoma. She testified that she tried to remain happy and cheerful, for instance by watching serials on TV, but soon – she said – "the reality irritates." Shweta, a patient who was 29 years old and was diagnosed with soft-tissue sarcoma of the pelvis with metastases in the lungs and brain, told about her approach: "I don't take stress. I don't think about the future." And generally, this was true, although she could not entirely avoid thinking of the future. When that happened, she used to shift to denial.

Denial occurs when a patient disagrees with the physicians regarding diagnosis and prognosis. Patients may find it hard to come to terms with the reality of a life-threatening disease. Therefore, they may prefer to believe that their physician has made a mistake; or they may convince themselves that they have not heard or understood what the doctor has said. Several signs may indicate that a patient is in denial. First, a patient may express an unrealistic prognosis. Shweta once said: "My chance to get fully cured is 60%." Her medical file told otherwise. This statement was all the more remarkable given the fact that Shweta was a physiotherapist by profession and, thus, had a medical background. Second, patients may opt for alternative treatment aimed at cure. Our patients most often tried Ayurveda or they went to another hospital where curative but futile and often burdensome treatment was offered to them. These patients had understood the diagnosis from the treating physician, but believed that this physician was mistaken regarding the diagnosis or the possibilities for treatment. Satendra, the husband of Geetika (38 years), a patient with CA rectum who was trying Ayurvedic treatment, expressed the feelings of these patients very well in his brief response when we asked him why his wife was taking Ayurvedic medicine. "We have to do something", he said. At the hospital they were only getting palliative treatment. But, for him and his wife the thought that no more curative treatment was administered was unacceptable. They felt that they simply had to try something else. Third, patients who are in denial may express unrealistic plans for the future. Shweta, for instance, spoke about living with her husband in China and working as a physiotherapist after her cure, notwithstanding the fact that she was in a very advanced stage of her disease.

Denial is very common among palliative care patients. This may be the reason why Kübler-Ross made it the first stage of her five stages of grief. Yet, we also have to beware of not misinterpreting patients' signs and conclude to easily that a patient is in denial. In many ways, the Indian palliative care context differs from the Western context from which much of our understanding of terminally ill patients' dealing with diagnosis and prognosis originates. A necessary condition for denial is that the patient has received proper understandable information. When patients enter palliative care in India, often this has not been the case. Physicians, although providing correct information, may not have spoken in a language and with terms the patient could comprehend. This occurs not rarely when the patient is uneducated. It is also possible that no physician has ever taken the time to inform the patient, or that a doctor only informed the relatives who fearing that knowledge about the disease would make the patient loose hope subsequently hid this information from the patient. Some patients may also have so much respect for the physicians and nurses that they do not want to

bother them with questions regarding their disease. Due to this reluctance the true nature of their disease may remain unknown to them.

We also should be aware that denial almost never occurs on its own. It is closely connected with hope and the level of acceptance which a patient has reached. Denial may be a way for patients to keep their eager hope for a cure alive and prevents them from accepting their medical condition. However, what interests us here most is that through its connection with hope and acceptance, denial, but also suppression, and spirituality interrelate.

Hope

In our study, we observed that hope can take various forms among terminally ill patients. Sometimes patients have learned to live with their disease and they only hope for some good time in the future. These patients somehow know that the illness will not go away. They hope that with the right (palliative) care they will be able to have some nice and enjoyable moments with their family and friends before they die. This idea was once expressed by Geetika's husband when she had been readmitted to the ward because her pain and drowsiness had returned. He said: "Good days go. Bad days go. Nothing is permanent. … Good days will come also for the treatment." He realized that his wife was dying and he was distressed because of her pain and suffering. But at the same time, he saw the good care which she received at the hospital and he expressed their shared hope that after her discharge they would have some good moments together as a family.

It is this kind of hope which doctors consciously or unconsciously stimulate when a terminally ill patient asks for curative treatment. When confronted with that question, palliative care physicians with much experience often respond "We will do everything we can to make you feel comfortable." With such an answer the physician tries to reassure the patient that he has some good time ahead of him and that he can rightly hope for a good quality of life.

Yet this is not the kind of hope which we most often saw among our patients. Invariably until the very last day, patients kept hoping that somehow, somewhere a cure for their treatment would be possible. This hope was nurtured by the availability of alternative treatment options, most often in the form of Ayurvedic therapies, but also curative treatment which is offered in private hospitals even at a stage when the patient is highly unlikely to benefit from it. Lack of comprehensible information too allowed the patients to hope for a cure. Many patients felt that the information which they had received regarding their medical condition was not clear. Yet, they were often reluctant to ask more information directly to the doctors. Moreover, information was hidden by relatives who believed it would cause distress and depression, and in that way hasten death. As mentioned above, many patients who are admitted to palliative care services in India, have not been informed about their condition for various reasons. This allows them to actively nurture hope for a cure, especially when they connect this hope with their faith in God.

Very often, patients derived hope for a cure from their strong faith in God. The case of hope for a cure very clearly illustrates how spirituality strongly determines patients' attitudes to their disease. Many Hindu, Muslim, Christian and Sikh patients saw themselves as people who throughout their life had been faithful to God. They held the belief that God would finally listen to their prayers and eventually grant cure.

This Hope for a cure was not always correctly understood by treating physicians and nurses. It was regularly mistaken for denial or lack of understanding. This can be illustrated by the case of the 68-year old Ramesh, who was suffering from Ca prostate with metastases. In our conversations, he had expressed awareness that his disease was there to stay and that he would eventually die with it. Yet, we also heard him repeatedly asking to the young physician on duty whether really no curative treatment was there for him at all. At one moment, the very busy physician lost his temper and said: "I have already explained you everything so many times. So what is the use of asking it again?" What this physician did not realise is that for Ramesh, his question was not useless at all. Ramesh had very well understood what the doctor had kindly and painstakingly explained to him. But at the same time, he had not given up the hope that maybe once he would get a different answer. Hope made him to ask the same question again and again and again.

The distinguishing line between denial and hope for a cure is often very thin and the two also mutually reinforce each other. A patient who denies his illness will find it very easy to hope that a cure is possible. And an all-pervasive hope driven, for instance, by a strong belief that God will come to his rescue, can stimulate a patient to deny his illness. Moreover, some signs such as searching for curative treatment can be an indication of both denial and hope. Thus, on the one hand, there is a some overlap between denial and hope for a cure. On the other hand, denial is a much more active process in which a patient shuts himself off from everything which could possibly confirm the illness. A patient who has hope, hesitantly looks for sources of support, such as a reassuring word of a trusted physician, as in Ramesh' case, or, as the studied patients more often did, a sign from God. Great was the disillusion when that divine sign did not come and the unstoppable disease progressed.

Acceptance

With the progress of the disease, our patients sooner or later had to recognise that they had the disease and had to find ways to face this fact. The road to this acceptance is a long and difficult process. For many patients, anger, frustration and depression were an integral part of it. This was particularly the case for those patients who had put all their trust in God. These patients felt at a loss when the hoped for cure did not materialise. For some of them, this spiritual crisis contributed to their depression. They directly or indirectly indicated that they wanted to die, rather than living with their disease. "If God does not want to cure me," they argued, "He can take me up."

The spiritual disillusion caused by the feeling that God had left them when they needed him most, combined with the inability to find a satisfactory answer to questions such as "Why am I not getting better?" and "Why does God not cure me?" made patients to be angry at God, or even wonder whether He exists at all. Patients testified, for instance, that they were no longer able to pray. Unresolved spiritual issues made it hard for these patients to accept their condition.

For other patients, however, spirituality turned out to be a source of support. A few Hindu patients with a philosophical inclination referred to the theory of *karma* in an attempt to understand the reason behind their suffering. They argued that maybe in a previous life they had done something wrong and their current illness was a punishment for that. But always, they said this hesitatingly. They were never fully sure whether that was indeed the right answer.

Conclusion

Our study has revealed that spirituality can exert a large influence on how patients emotionally respond to their disease. In this context, spirituality is not the only factor, but through its interaction with other factors, such as lack of information, availability of alternative treatment options and attitudes of relatives, spirituality determines patients' attitudes to their disease. It is important to see that in this process the influence of spirituality is not one-directional. For some patients, spirituality may be a source of support on their way to acceptance of their disease by providing some kind of answer to their existential questions. The fact that some patients derived consolation from the *karma*-theory illustrates this. Yet, spiritual views make many other patients to move in the opposite direction away from acceptance. Spirituality may, for instance, strongly support hope for a cure and in that context interact with denial. This is particularly the case among patients who focus on a loving God who will grant them cure. Such patients are also at risk of facing a spiritual crisis when they finally realise that will not get better. Due to the emotional disturbance caused by the crisis, patients may feel lost and lonely and acceptance of the disease may become even harder for them. In this sense, it is obvious that spirituality does matter in end of life care. When palliative care teams are evaluating a patient they should pay attention to spiritual problems and concerns, and carefully assess how these interact with other factors. Effective spiritual counselling will only be possible after such a careful assessment.

REFERENCES

1. WHO Definition of Palliative Care. 2013. (Accessed 26 November, 2013, at http://www.who.int/cancer/palliative/definition/en/.)
2. Paley J. Spirituality and secularization: nursing and the sociology of religion. J Clin Nurs 2008;17:175-86.
3. Kübler-Ross E. On death and dying: What the dying have to teach doctors, teachers, nurses, and their own family members. New York: Macmillan; 1969.
4. Kübler-Ross E. Questions and answers on death and dying. London: Collier-Macmillan; 1974.
5. Elisabeth Kübler-Ross Foundation. (Accessed 27 November, 2013, at http://www.ekrfoundation.org/.)